# **Complete Summary**

#### **GUIDELINE TITLE**

Guideline for Alzheimer's disease management.

# **BIBLIOGRAPHIC SOURCE(S)**

California Workgroup on Guidelines for Alzheimer's Disease Management. Guideline for Alzheimer's disease management. Chicago (IL): Alzheimer's Association; 2008 Apr. 61 p. [396 references]

#### **GUIDELINE STATUS**

This is the current release of the guideline.

It updates a previously published version: California Workgroup on Guidelines for Alzheimer's Disease Management. Guideline for Alzheimer's disease management. Chicago (IL): Alzheimer's Association; 2002.

#### \*\* REGULATORY ALERT \*\*

# FDA WARNING/REGULATORY ALERT

**Note from the National Guideline Clearinghouse**: This guideline references a drug(s) for which important revised regulatory and/or warning information has been released.

June 17, 2008, Antipsychotics (conventional and atypical): The U.S. Food and Drug Administration (FDA) notified healthcare professionals that both conventional and atypical antipsychotics are associated with an increased risk of mortality in elderly patients treated for dementia-related psychosis. The prescribing information for all antipsychotic drugs will now include information about the increased risk of death in the BOXED WARNING and WARNING sections.

## **COMPLETE SUMMARY CONTENT**

\*\* REGULATORY ALERT \*\*

**SCOPE** 

METHODOLOGY - including Rating Scheme and Cost Analysis
RECOMMENDATIONS
EVIDENCE SUPPORTING THE RECOMMENDATIONS
BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS
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#### SCOPE

# **DISEASE/CONDITION(S)**

Alzheimer's disease

## **GUIDELINE CATEGORY**

Counseling Evaluation Management Treatment

#### **CLINICAL SPECIALTY**

Family Practice Geriatrics Internal Medicine Neurology Nursing Psychiatry

## **INTENDED USERS**

Advanced Practice Nurses
Allied Health Personnel
Health Care Providers
Nurses
Occupational Therapists
Physical Therapists
Physician Assistants
Physicians
Psychologists/Non-physician Behavioral Health Clinicians
Social Workers

## **GUIDELINE OBJECTIVE(S)**

To provide assistance to Primary Care Practitioners (PCP)s in offering comprehensive care to patients with Alzheimer's disease and those who care for them over the course of their illness

#### **TARGET POPULATION**

Patients with Alzheimer's disease

#### INTERVENTIONS AND PRACTICES CONSIDERED

#### **Assessment**

- 1. Assessment, documentation, and monitoring
  - Daily functioning
  - Cognitive status
  - Comorbid medical conditions
  - Behavioral symptoms, psychotic symptoms, or depression
  - Medications, both prescription and non-prescription
  - Living arrangements (safety, care needs, and abuse and/or neglect)
  - Need for palliative and/or end-of-life care planning
- 2. Frequency of reassessment
- 3. Identification of the primary caregiver and assessment of the adequacy of family and other support systems
- 4. Assessment of the patient's decision-making capacity identification of whether a surrogate has been identified
- 5. Identification of the patient's and family's culture, values, primary language, literacy level, and decision- making process

#### **Management/Treatment**

- 1. Development and implementation of an ongoing treatment plan with defined goals
- 2. Non-pharmacological treatment
  - Referral to community based services
  - Environmental modification
  - Task simplification
  - Appropriate activities
- 3. Pharmacological treatment
  - Therapies for cognition (cholinesterase inhibitors, N-methyl-Daspartate antagonists)
  - Therapies for behavioral symptoms and mood disorders (antipsychotic medications, mood stabilizers [anti-agitation agents], antidepressants)
- 4. Treatment of comorbid conditions
- 5. Palliative and end-of-life care

# **Education/Support**

- 1. Education and support for patients and carers
- 2. Referral to support services and organization for carers
- 3. Involvement of carers and patients in planning, including end-of-life decisions

# **Legal Considerations**

- 1. Legal and financial planning
- 2. Structured capacity evaluations
- 3. Assessment of abuse
- 4. Reporting diagnosis to appropriate authorities (in relation to driving)

#### **MAJOR OUTCOMES CONSIDERED**

- Mortality
- Cognitive level
- Functional level
- Incidence of abuse and neglect
- Coping ability of families and caregivers
- Rate of disease progression

#### **METHODOLOGY**

# METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources) Hand-searches of Published Literature (Secondary Sources) Searches of Electronic Databases

## **DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE**

The 2008 Guideline updates the California Workgroup's 2002 version (itself a revision of the original 1998 publication), which relied upon a review of more than 222 articles published between 1998 and 2002, in addition to the 275 articles which formed the basis of the original guideline.

For the 2008 revision, a literature search was performed using the PubMed and PsycInfo databases. Search terms included "Alzheimer" plus "treatment," "assessment," "systematic," "meta-analysis," "primary care," "early-stage," and "late-stage," limited to peer-reviewed journals. In addition, the Cochrane Database of Systematic Reviews was searched using the term "Alzheimer." Articles published between 2002 and 2008 were reviewed, as well as seminal articles published prior to that period and key sources cited in the previous versions of this Guideline. Links to related studies were explored, as were additional studies by authors of those found through the initial search, major research programs conducted by those authors, and other references provided by members of the California Workgroup. Further studies were located using the ancestry method (i.e., searching the references sections of studies obtained through the procedures described above). Selected articles, including reviews and meta-analyses, reports of relevant clinical trials and other intervention studies, and previously published guidelines, were furnished to the Workgroup members responsible for each of the four sections of the 2008 Guideline.

#### NUMBER OF SOURCE DOCUMENTS

Not stated

# METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus (Committee)

# RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

#### METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses Systematic Review

#### **DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE**

Not stated

#### METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus (Consensus Development Conference)

# DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

The 2008 Guideline for Alzheimer's Disease Management is based on a systematic review of relevant studies and meta-analyses by the California Workgroup on Alzheimer's Disease. The recommendations found in this Guideline were based on the best evidence available. When a thorough search turned up insufficient or inconsistent data with respect to a specific aspect of Alzheimer's Disease management, recommendations were made on the basis of expert opinion and Workgroup consensus arrived at through the process described below.

The members of the California Workgroup met in November 2007 to discuss the materials and the major issues they raised and to reach a consensus with respect to proposed recommendations for each of the four subject areas covered by the Guideline. The four subgroups developed drafts of their respective sections of the full report, which were circulated among all the Workgroup members for review and editing in an iterative process that, after several rounds, resulted in a consensus document. During this period, members submitted additional articles not found through the initial searches, which were incorporated in subsequent drafts where relevant.

## RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

#### **COST ANALYSIS**

A formal cost analysis was not performed and published cost analyses were not reviewed.

#### METHOD OF GUIDELINE VALIDATION

Internal Peer Review

#### **DESCRIPTION OF METHOD OF GUIDELINE VALIDATION**

#### **RECOMMENDATIONS**

#### MAJOR RECOMMENDATIONS

#### **Assessment**

- Conduct and document an assessment and monitor changes in:
  - Daily functioning, including feeding, bathing, dressing, mobility, toileting, continence, and ability to manage finances and medications.
  - Cognitive status using a reliable and valid instrument.
  - Comorbid medical conditions, which may present with sudden worsening in cognition, function, or as change in behavior.
  - Behavioral symptoms, psychotic symptoms, or depression.
  - Conduct and document an assessment and monitor changes in medications, both prescription and non-prescription (at every visit).
  - Living arrangements, safety, care needs, and abuse and/or neglect.
  - Need for palliative and/or end-of-life care planning.
- Reassessment should occur at least every 6 months, and sudden changes in behavior or increase in the rate of decline should trigger an urgent visit to the Primary Care Practitioner (PCP).
- Identify the primary caregiver and assess the adequacy of family and other support systems, paying particular attention to the caregiver's own mental and physical health (see Table 1, below).

# **Table 1: Fundamental Principles of Caregiver Assessment**

## Caregiver assessment should:

- Recognize, respect, assess, and address their needs
- Embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver
- Result in a plan of care, developed collaboratively with the caregiver, that identifies services to be provided and intended measurable outcomes
- Be multidimensional, reflect culturally competent practice, and be updated periodically
- Assess the patient's decision-making capacity and determine whether a surrogate has been identified.
- Identify the patient's and family's culture, values, primary language, literacy level, and decision-making process.

#### Treatment

- Develop and implement an ongoing treatment plan with defined goals.
   Discuss with patient and family:
  - Use of cholinesterase inhibitors, N-methyl d-aspartate receptor (NMDA) antagonist, and other medications, if clinically indicated, to treat cognitive decline.

- Referral to early-stage groups or adult day services for appropriate structured activities, such as physical exercise and recreation.
- Treat behavioral symptoms and mood disorders using:
  - Non-pharmacologic approaches, such as environmental modification, task simplification, appropriate activities, etc.
  - Referral to social service agencies or support organizations, including the Alzheimer's Association's MedicAlert® + Safe Return® program for patients who may wander.
- IF non-pharmacological approaches prove unsuccessful, THEN use medications, targeted to specific behaviors, if clinically indicated. Note that side effects may be serious and significant.
  - To summarize specific recommendations with respect to pharmacologic management of behavioral symptoms:
    - Prior to initiating treatment with new medication, consider whether the behavior maybe caused or exacerbated by a current medication.
    - Delirium, pain, or an acute medical condition (e.g., *urinary tract infections* [UTIs], constipation, pneumonia) should be ruled out as a cause of the behavior.
    - Medications used for managing behavioral symptoms should be used cautiously. Little evidence exists to support their efficacy, with the exception of atypical antipsychotics (Schneider, Dagerman, & Insel, 2005).
    - Systematic trials of single agents should be tried rather than the use of multiple agents.
    - Start with low doses and increase gradually until a therapeutic effect is achieved, which may require a few weeks (Grossberg & Desai, 2003).
    - Periodically reduce psychopharmacologic agents after behavioral symptoms have been controlled for 4 to 6 months to determine whether continuing pharmacotherapy is required (American Psychiatric Association, 2007; Cummings & Benson, 1992; Lyketsos et al., 2006).
- Provide appropriate treatment for comorbid medical conditions.
- Provide appropriate end-of-life care, including palliative care as needed.

#### **Patient and Family Education and Support**

- Integrate medical care with education and support by connecting patient and caregiver to support organizations for linguistically and culturally appropriate educational materials and referrals to community resources, support groups, legal counseling, respite care, consultation on care needs and options, and financial resources. Organizations include:
  - Alzheimer's Association (800) 272-3900 www.alz.org
  - Caregiver Resource Centers (800) 445-8106
  - www.caregiver.org
  - Or your own social service department
- Discuss the diagnosis, progression, treatment choices, and goals of
   Alzheimer's disease care with the patient and family in a manner consistent

- with their values, preferences, culture, educational level, and the patient's abilities.
- Pay particular attention to the special needs of early-stage patients, involving them in care planning, heeding their opinions and wishes, and referring them to community resources, including the Alzheimer's Association (see Table 2, below).
- Discuss the patient's need to make care choices at all stages of the disease through the use of advance directives and identification of surrogates for medical and legal decision-making.
- Discuss the intensity of care and other end-of-life care decisions with the Alzheimer's disease patient and involved family members while respecting their cultural preferences (see Table 3, below).

# **Table 2: Checklist for Early-Stage Care**

- Conduct regular follow-up assessments to monitor the patient's cognitive status and abilities, as well as effectiveness and side effects of any pharmacological treatments.
- Discuss implications with respect to work, driving, and other safety issues (e.g., risk of falls; see Appendix F in the original guideline document for a safety assessment checklist).
- Recommend the following non-pharmacological interventions (preferably in combination) to protect and promote continuing functioning, assist with independence, and maintain cognitive health:
  - 1. Physical exercise, preferably aerobic exercises if tolerated (or less-strenuous exercises that promote strength, balance, and coordination, such as Tai Chi)
  - 2. Cognitive therapies, preferably focusing on cognitive training and rehabilitation or memory rehabilitation
  - 3. Comprehensive recreational therapies (e.g., art, writing, social engagement, individualized hobbies)
  - 4. Support group participation (continuous, not time-limited)
  - 5. Programs to improve sleep, such as NITE-Alzheimer's Disease (McCurry et al., 2005)
  - 6. Driving evaluations at least every 6 months, including an on-road test with an experienced driving specialist
  - 7. Individualized instruction in activities to promote independence (e.g., cell phone usage, computer e-mail programs, etc.)
  - 8. Electronic reminder and monitoring programs (if not cost-prohibitive)

Table adapted from Family Caregiver Alliance, 2006

## Table 3: Factors to Consider in Planning for End-of-Life Care

- Maximize options for comfort care through hospice referral.
- Avoid futile care and prolongation of the dying process.
- Discuss the benefits and risks of tube feeding.
- Review and simplify the patient's medication regimen.

## Table 3: Factors to Consider in Planning for End-of-Life Care

• Assess and respect the patient's and family's cultural values and preferences.

Table adapted from Wolf-Klein et al., 2007

# **Legal Considerations**

- Planning: Include a discussion of the importance of basic legal and financial planning as part of the treatment plan as soon as possible after the diagnosis of Alzheimer's disease.
- Capacity Evaluations: Use a structured approach to the assessment of patient capacity, being aware of the relevant criteria for particular kinds of decisions.
- Elder Abuse: Monitor for evidence of and report all suspicions of abuse (physical, sexual, financial, neglect, isolation, abandonment, abduction) to Adult Protective Services, Long Term Care Ombudsman, or the local police department, as required by law.
- Driving: Report the diagnosis of Alzheimer's disease in accordance with the law.

#### **Summary of Recommendations by Disease Stage**

# **Early Stage Recommendations**

Patients in early-stage Alzheimer's disease (AD) have unique concerns. AD may progress slowly in the early stage. Follow up two months after diagnosis and every six months thereafter. Pay particular attention to the special needs of early-stage patients, involving them in care planning and referring them to community resources. Discuss implications with respect to work, driving, and other safety issues with the patient. Initiate pharmacologic therapy early. Recommend interventions to protect and promote continuing functioning, assist with independence, and maintain cognitive health including physical exercise, cognitive stimulation and psychosocial support.

# Late Stage and End-of-Life Recommendations

As the patient's dementia worsens and the ability to understand treatments and participate in medical decision-making declines, care shifts to focus on the relief of discomfort. The advisability of routine screening tests, hospitalization, and invasive procedures, including artificial nutrition and hydration, will depend upon previously discussed care plan and the severity of the dementia. Predicting the end-of-life for a patient with severe AD is difficult. Referral to hospice should be considered.

### CLINICAL ALGORITHM(S)

None provided

#### **EVIDENCE SUPPORTING THE RECOMMENDATIONS**

#### REFERENCES SUPPORTING THE RECOMMENDATIONS

References open in a new window

#### TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of evidence supporting the recommendations is not specifically stated.

## BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

#### **POTENTIAL BENEFITS**

- Effective treatment and management of patients with Alzheimer's disease (AD) based on stage of disease
- Appropriate support for caregivers of patients with AD

#### **POTENTIAL HARMS**

Side effects of pharmacological therapy (see the original guideline document for details on side effects of specific medications)

#### CONTRAINDICATIONS

### **CONTRAINDICATIONS**

Thioridazine should not be prescribed for Alzheimer's disease (AD) patients. Avoid other typical antipsychotics listed in Table T7 of the original guideline document in AD psychiatric behavioral conditions as well.

# **QUALIFYING STATEMENTS**

#### QUALIFYING STATEMENTS

This Guideline presents core care recommendations for the management of Alzheimer's disease. It assumes that a proper diagnosis has been made using reliable and valid diagnostic techniques. The main audience for the Guideline is primary care practitioners. However, many of the activities recommended in the Guideline do not require a physician and can be done by other members of the treatment team (care managers, nurses, community support organizations) working closely with the patient and caregiving family. The recommended activities do not have to be done in one visit.

#### **IMPLEMENTATION OF THE GUIDELINE**

#### **DESCRIPTION OF IMPLEMENTATION STRATEGY**

An implementation strategy was not provided.

## **IMPLEMENTATION TOOLS**

Chart Documentation/Checklists/Forms
Pocket Guide/Reference Cards
Resources

For information about <u>availability</u>, see the "Availability of Companion Documents" and "Patient Resources" fields below.

# INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

#### **IOM CARE NEED**

End of Life Care Living with Illness

#### **IOM DOMAIN**

Effectiveness Patient-centeredness

## **IDENTIFYING INFORMATION AND AVAILABILITY**

# **BIBLIOGRAPHIC SOURCE(S)**

California Workgroup on Guidelines for Alzheimer's Disease Management. Guideline for Alzheimer's disease management. Chicago (IL): Alzheimer's Association; 2008 Apr. 61 p. [396 references]

## **ADAPTATION**

Not applicable: The guideline was not adapted from another source.

## **DATE RELEASED**

1998 (revised 2008 Apr)

## **GUIDELINE DEVELOPER(S)**

Alzheimer's Association - Disease Specific Society

# **SOURCE(S) OF FUNDING**

Alzheimer's Association

# **GUIDELINE COMMITTEE**

## **COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE**

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## FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

#### **GUIDELINE STATUS**

This is the current release of the guideline.

It updates a previously published version: California Workgroup on Guidelines for Alzheimer's Disease Management. Guideline for Alzheimer's disease management. Chicago (IL): Alzheimer's Association; 2002.

#### **GUIDELINE AVAILABILITY**

Electronic copies: Available in Portable Document Format (PDF) from the Alzheimer's Association Web site.

Print copies: Available from the Alzheimer's Association, National Office, 225 N. Michigan Ave., Fl. 17, Chicago, IL 60601-7633, Phone: 1-800-272-3900

#### **AVAILABILITY OF COMPANION DOCUMENTS**

The following are available:

- Guideline for Alzheimer's disease management. National summary. 2 p. 2008
   Apr. Electronic copies: Available in Portable Document Format (PDF) from the Alzheimer's Association Web site.
- Guideline for Alzheimer's disease management. California summary. 2 p. 2008 Apr. Electronic copies: Available in Portable Document Format (PDF) from the <u>Alzheimer's Association Web site</u>.
- Provider checklist for treating a confused elder. 1 p. Available in Portable Document Format (PDF) from the <u>Alzheimer's Association Web site</u>.

Print copies: Available from the Alzheimer's Association, National Office, 225 N. Michigan Ave., Fl. 17, Chicago, IL 60601-7633, Phone: 1-800-272.3900

Additionally, tools for functional, cognitive, nutritional, behavioral, depression, safety, and caregiver assessment, as well as several California state forms, are available in the appendices to the <u>original guideline document</u>.

#### **PATIENT RESOURCES**

None available

# **NGC STATUS**

This NGC summary was completed by ECRI on September 23, 2008. The information was verified by the guideline developer on October 21, 2008.

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